DOCUMENT RESUME

ED 223 050 EC 150 352

AUTHOR Scheiber, Barbara; Moore, Cory
TITLE Practical Advice to Parents: A Guide to Finding Help for Children with Handicaps.
INSTITUTION Parents Campaign for Handicapped Children and Youth, Washington, D.C. Closer Look.
SPONS AGENCY Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE 81
NOTE 29p.
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Attitudes; Clinical Diagnosis; *Disabilities; Elementary Secondary Education; Financial Support; Parent Associations; *Parent Role; Parent Teacher Cooperation; Resources; Special Programs
IDENTIFIERS Parent Materials

ABSTRACT

The booklet offers information to help parents find resources for their handicapped children. Following a brief discussion of the difficulties of having a handicapped child is a chapter with tips about diagnosis. Among the suggestions offered are insisting on a clear and complete interpretation of all diagnostic reports and checking the library for books on helping the child at home. A chapter on educating the handicapped child deals with P.L. 94-142 (the Education for All Handicapped Children Act), guidelines for considering a specific program or working with the school system in developing an educational plan, tips for strengthening the parent-teacher relationship, and things to do when the school system has not provided the program your child needs. Another chapter considers some of the opportunities that are open to disabled individuals in the areas of higher education, vocational rehabilitation, employment, and independent living. Sources of financial support are addressed in the sixth chapter, while a seventh chapter mentions several information sources. The two final chapters discuss reasons for joining a parent group and changes in attitudes toward the handicapped. (SW)

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Practical Advice to Parents

a guide to finding help for children with handicaps

by Barbara Scheiber and Cory Moore

Closer Look

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A PROJECT OF
Parents' Campaign for Handicapped Children and Youth

Box 1492
Washington, D.C. 20013

EC150352

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Foreword

Closer Look is a national center for parents of children with mental, physical, and emotional handicaps. The help we offer is information—information about the many different kinds of resources that individuals with handicaps must have in order to learn, to grow, to participate as fully as possible in life. We hear from people throughout the country and we respond by telling them about places and people to turn to—organizations, agencies, and individuals that can help in locating programs and coping with problems.

In the course of our work, we receive many thousands of letters from parents who tell us of those first difficult days of learning about their child's handicapping condition and then seeking appropriate programs and services. We know that in the past few years, changes have taken place that make a parent's search not quite as lonely and discouraging as it once was. Educational systems are offering programs geared to the needs of the individual child. Parent groups and other disability-related organizations have become more effective in their efforts to gain community understanding and response. Men and women with disabling conditions have banded together to become a strong force for progress. Gradually, barriers are coming down—barriers that have kept children and adults with handicaps out of society's mainstream, isolated from the world of so-called "normal" people.

Although the last few years have brought new opportunities and increased help and understanding, parents still feel very much on their own when it comes to raising a child with a handicap. We know that being a parent takes courage, persistence, ingenuity, commitment—and humor. It involves not only finding, working with and monitoring services, but also handling difficult management problems at home, encouraging children who suffer repeated disappointments to keep trying, maintaining one's own spirit and hope.

Parents begin with no special preparation for bringing up a "special" child. They start out with only bits of information, or none at all, and then must teach themselves, as well as other people. We at Closer Look have learned, from parents who have been through the mill, how some of the challenges that lie ahead can be met constructively. We want to pass this practical advice on to you.

These are not "how to" instructions for instant solutions. They are suggestions to use as you go about the important job of helping your child discover his strengths, enjoy life, grow toward independence.

Parent to parent

No parent is ever prepared for the shock of learning that his child has special needs. Whether the handicapping condition is diagnosed when your baby is born or suspected over time and later confirmed, whether it is the result of a birth injury, an illness, or an accident, your reactions will be very much the same. Feelings of panic, of fear, of anger and disappointment are normal and natural. You will know grief and sadness, confusion and resentment. You will be tired and depressed; you will want to draw away from others, even those family members and friends who have been closest to you. You will ask questions that have no answers: "Why me?"; "Why my child?"

The road ahead isn't easy. The going will often be rough. Your burdens *are* heavy. You need time to recover, to adjust and slowly muster the inner strength and determination to help your child grow. The fact that you are reading these words shows that you have gotten beyond one necessary first step—realizing that a handicap exists. You will know when you are ready to take the next steps.

It takes guts, drive, and energy to move past the hurt to the doing and you may need the assistance of others to get there. Our world does not prepare us for an ongoing crisis and it may not be easy to ask for a hand. But it is necessary. To help your child, you will need support for yourself. Seek out other parents who know, from their own experience, what you are going through. They can give you a rare measure of understanding and perspective. Read and learn from the many fine books by parents and professionals. Look for doctors, counselors and other professional helpers who respond to your needs as a parent and a person. Take time off from your everyday routines and responsibilities to renew a sense of who you are.

Eventually you will learn that there can still be joy, love, happiness, laughter, and opportunities for growth and fulfillment in your life. You will find new courage and ability, strength and awareness. You will move on.

Tips about diagnosis

Whether your child is diagnosed at birth or the suspicion of a disabling condition comes later, there are important decisions to be made about procedures to follow and people to see. One doctor will usually not be enough to take care of all your child's needs. You will want to choose appropriate professionals—neurologist, psychologist, audiologist, physical therapist, or other specialists—who can examine your child and give you as complete a diagnosis as possible. Today there are more and more "one stop" clinics at universities and training hospitals where experts in many fields work as a team to determine what the disability is and suggest what can be done to help.

Locating the professionals you need may seem difficult at first, but there are people who can point the way. Check your county health department or school system for free diagnostic services. The reference room of public libraries will probably have directories of local, state and national resources and a reference librarian who can help you in your quest. The yellow pages of your telephone book may yield suggestions under particular medical or social services headings. Parent organizations such as the local Association for Retarded Citizens or the local Association for Children and Adults with Learning Disabilities are often good sources of information on places to go and what to expect when you get there. And, of course, your own pediatrician or family doctor will be able to send you to a particular specialist, a diagnostic clinic, or a teaching hospital for testing and evaluation. That same pediatrician or family doctor will probably act as your primary physician, referring you to others, coordinating the information as it is received, and helping you find answers to your questions. Be sure that your child's primary physician is someone with whom you feel comfortable, someone who understands your needs as well as your child's.

Before your first visit to a specialist or team of specialists, invest in a large and sturdy notebook. This notebook will be an important ally for you and your child as you learn about and explore existing services. It is your record of today and your sourcebook for tomorrow. Record useful names, addresses and phone numbers, dates of visits, who was at meetings and what they said. Write down questions in advance of appointments, and keep notes of answers and recommendations. Some parents arrange to bring tape recorders to conferences with doctors and school officials so that their records will be accurate. Use your notebook to file test results, reports, and your own observations. (Remember to date them.)

As you meet new specialists and professionals, you will be asked many of the same questions. In the early days, you will easily carry this information in your head; as time goes on and changes occur, your reference notebook will prove its value over and over again.

When you talk with diagnosticians, be sure to explain your concerns as fully as possible. You know your child best and can supply information about him that nobody else can. Trust yourself and your perceptions of the child you live with and observe daily. Your observations about his or her behavior are an essential contribution to the diagnostic process.

As a consumer, you should insist upon a clear and complete interpretation of all diagnostic reports. Explanations to you should be in understandable language, not in professional terminology. Ask all the questions you feel you need to ask. Ask for written statements of all testing procedures. You should know why tests are given and what information they are expected to yield. Also, be sure to get a written report of the results. File all of this in your notebook. It will be of great value in following up recommendations, selecting appropriate programs and discussing your child's needs with other people. Always keep in mind that *you* are the leading expert on your child's special needs and problems. These reports are an essential part of the equipment you must have to do your job well.

Remember that a diagnosis and assessment should indicate, as far as possible, what kinds of help—in terms of educational programs, special treatment and activities—your child needs in order to develop to his full potential. A clinician may give your child a label, but this is only a convenient way to define a condition. A label by no means says all there is to say about your child, and it is not the final word. He is, first and foremost, a child, a unique, interesting human being who can change and respond in surprising and wonderful ways. Furthermore, a label describes a child's *dis*abilities, not his abilities, not the things he *can* do. You and your child need to look not only at the limitations on his capabilities, but at the ways he *can* grow, *can* express himself, and *can* gain satisfaction. And the job of the diagnostician should be to inform you of the special, extra, and individual services that will offer your child these opportunities.

The diagnostician often will be able to direct you to special services that are recommended, such as a preschool program, or speech therapy, motor coordination training or infant stimulation. More and more school systems are sponsoring infant programs for babies with handicaps; trained therapists can help you learn the special handling and teaching techniques that can be continued at home. If your diagnostician does not know exactly where you should go, call the special education department of your city or county school system and the local health department. Or there may be a

privately operated treatment center, such as Easter Seal, offering services nearby.

If you live in a small community and there is no infant or preschool program convenient to you, be sure to check with your librarian for some of the excellent books describing things parents can do at home to help babies with developmental delays; many have drawings or photographs to help you learn these important activities.

Of course, the local parent group concerned with your child's handicap is an excellent source of information about available services, as well as other ideas for helping your child. Ask about such a group. (If you are unable to locate one in your area, write for our listings of parent organizations in your state.)

While the importance of testing, diagnosing, assessing and evaluating your child cannot and should not be minimized, do keep firmly in mind that no one can tell you absolutely what the future will hold for your child. A test or diagnosis can only result in a "best guess" and not a lifetime prophecy. Early childhood programs have made a considerable difference in the development of many babies and young children. The stimulation and involvement of a caring family will often have exciting effects on a child's growth. Time and a good educational program based on your child's individual needs can have a real impact.

It is vital from the very earliest days for parents to realize their importance in the life of their child. You are your child's first teacher, the coordinator of his programs, the judge of whether or not things are working well. You must choose, evaluate, and make decisions. Always keep in mind that in the long run a competent parent will be the best asset your child will ever have. It may seem like too much responsibility at first, but you and your child can learn together, one day at a time.

When your child goes to school

We are living in a time of new opportunities for children with special needs. Not too long ago, most children with severe handicapping conditions were either excluded entirely from school programs or were educated in separate classes (most often, separate buildings) isolated from children attending regular schools.

Today, it is acknowledged that every handicapped child has the right to an education, regardless of the nature or severity of his or her disability. The passage of The Education for All Handicapped Children Act of 1975 (Public Law 94-142) was a historic event, heralding a new philosophy.

At the heart of this philosophy is the belief that every child *can* learn—even if learning takes place at a slow rate, in small steps. The key is to find out—by thorough diagnosis and assessment of a child's abilities as well as difficulties—*how* he learns best, what particular approaches will help him move ahead to new achievements, what supports or aids can make a difference. With this kind of understanding, a school program can be designed to give a handicapped child the special education services he or she must have in order to progress.

This view offers great hope for children who have handicaps. It says, in effect, that the school program must fit the child—not the other way around. The process of designing an appropriate program is a constantly evolving one. It calls for ongoing perception of a child's growing needs, respect for his individual worth.

This respect is reflected in another major breakthrough in education of children with handicaps—the assertion of their right to be educated in "the least restrictive environment." In simple terms, this means including a child who has a handicap in the most normal possible school setting: in a regular class, or if this is not feasible, in a program that offers the greatest possible opportunities for joining with non-handicapped peers.

Implementing all of these changes needs your participation as a partner in the educational process. You have a vital part to play in ensuring that your child's school years are successful and happy ones—and that they help him reach the best that is in him.

Some handicapping conditions don't show up until the child is confronted by the demands of school life. Until recent years, school-related handicaps too often went undetected and unhelped. Parents were (and sometimes still are) called "over-anxious" and "emotional" when they expressed worries about youngsters who were failing. Or their children were labelled "lazy," "spoiled" or just

"impossible." Fortunately, techniques for diagnosing learning disabilities and behavior problems are far more sophisticated than ever before. More is known about *how* to help children who are experiencing difficulties in school. If your child has a school-related handicap, or if the diagnosis came earlier and he or she is now in school, there is a great deal you can do.

By all means, ask for an appointment to talk to the teacher. This exchange may be very valuable in giving both you and the teacher a clearer picture of your child's academic and social needs, may lead to beneficial changes in attitude and approach, or may simply help to make the adjustment to school as smooth as possible.

If your child is having serious difficulties that persist despite efforts you and the teacher have made, ask that the teacher refer him for an evaluation. Or, the school may suggest to you that testing is necessary to understand the difficulty and see what help may be needed. Some schools have psychologists who do the necessary testing, some have teachers who are especially trained to do educational evaluations. You also can select a qualified specialist of your own choice either from a public agency or from private practice. If you do, be certain that the results of the evaluation are received by the school personnel responsible for making decisions about school placement.

Be sure you understand why particular recommendations are made. Do not hesitate to ask that test results be interpreted to you in clear, simple terms. It is most important to find out from the person who tests your child what strengths and assets he or she sees in your child, as well as what weaknesses and deficits may need attention. This will help you evaluate whatever school program is suggested, and also help your child find areas of activity in which he can feel increasingly successful and self-confident.

One of the key concerns about school placement is the extent to which your child will be going to school with non-handicapped students. With increased acceptance of children with special needs has come heightened awareness of the value of giving disabled and non-disabled children the greatest possible opportunity to grow and learn together. Many school systems have been successful in educating pupils with handicaps in local schools along with their own brothers and sisters and their neighborhood friends. Other localities have felt that incorporating special supplementary services into one building that houses only children with similar handicaps is more efficient.

You may be faced with several options. It's important to weigh them carefully.

Think about your child's needs and what setting will help him the most—in academic and social development, in self-reliance and self-esteem. Keep in mind that a child is first of all a child; his handicap should not define him. Children with handicaps can profit from observing non-handicapped children—how they behave and how they learn. Non-

handicapped children can learn, at an early age, a respect for individual differences. Brothers and sisters as well as parents of children with handicaps need not feel the lonely pang of the message that isolation from the mainstream delivers.

It is important, of course, that instructional procedures be adapted for specific needs and that appropriate services be provided to help your child learn. The services of a resource room for part of the school day, or even a self-contained classroom for most of the school day, may be most appropriate. If your child requires instruction in a separate classroom, think of other times during the day that he can interact with non-disabled schoolmates . . . on the playground, in the cafeteria, during music or art sessions, on school outings. Discuss these with the teacher. With encouragement and support (in some instances, the help of volunteers or aides), these periods can be a regular part of your child's program.

If your child must, for a period of time, be educated away from home in a separate facility, use vacations and weekends for opportunities to help him keep up with friends at home. Being in a separate school is only for a limited time, and it's important for you and the school to prepare the child to come back to his own community.

You should be involved in making decisions about the program that is designed for your child. If, after testing, he or she is found eligible for special education, it's your role to join with school representatives at a meeting to help develop the individualized education program (IEP) best suited to his or her needs. Public Law 94-142 specifically includes parents in the team that develops the IEP. Your knowledge of your child is vital in deciding short and long-term learning goals, choosing appropriate educational services and helping to monitor his progress toward meeting those learning goals. If you feel worried or unsure about this type of exchange with professionals, talk to other parents who have had the same experience. Please remember how much you have to offer, how much information you can supply about your child. And learn all you can about the types of services that will create a fruitful learning environment.

Speak up if you do not feel that a suggested program is suitable for your child. If you have serious questions, you should talk them over with someone who can help you, probably the professional who knows your child best. If, after your child is placed in a program, you become convinced that a change is needed, you should insist on a review of the situation. Find out the steps to take in your school district for requesting meetings or hearings at which school personnel and parents take a second look at decisions about class placement.

What to look for in a school program

There is probably no such thing as a perfect program. Although we certainly

don't advocate settling for whatever happens to be available, we know that nearly every program is going to require some compromise. More important is the realization that even the most well developed program needs you—the parent—as someone who stays aware of what's going on, who continues to discuss your child's progress and problems with his teacher, who finds ways that home and school can work together, who listens with sensitivity to your child's reactions and is alert to changing needs.

The following are some guidelines you can bear in mind when you are considering a specific program, or working with the school system in developing an educational plan for your child. They are not hard-and-fast criteria, but questions to help you weigh the various factors involved.

If a special classroom has been recommended, visit it. React to the atmosphere. Is it cheerful and relaxed? Is there an air of purposeful activity? Do you sense among the teaching staff a feeling of interest and enthusiasm for the children? Try to picture your child in the program. Would he fit in? Would he benefit from it? Imagine the setting from your child's point of view, with his particular handicap. For instance, if your child has a hearing impairment, imagine that you cannot hear and see how the classroom strikes you. How would his communication needs be met?

It is valuable to know about the training and experience of the staff responsible for your child's program. In some programs, graduate students or others who have not completed formal training in special education work under the guidance of fully trained professionals. In such instances, you should find out how the supervision is carried out. How often does the professional actually see the child? In what ways does he or she influence the classroom activity? Although academic degrees are important, it is good to remember that the best teaching is not necessarily done by those with the "best" qualifications. A great many people with no formal training are highly successful in working with people with handicaps.

In this connection, you might also find out about opportunities offered by the school for the staff to receive in-service training on an ongoing basis. Many school systems require or have strong incentives for advanced academic work for their staff.

Does your child require specific kinds of treatment, such as speech or physical therapy? If so, will they be provided? How? Will services be available on the premises, or will special trips be required? How often will services be offered each week? What kind of training and experience does the professional who conducts these sessions have?

Will your child be tested and re-evaluated at regular intervals? Will modifications be made if this program no longer appears to be suitable? Does this include placement in regular classes whenever appropriate?

How large a class will your child be in? Are there aides or other helpers (paraprofessionals, students) who can free the teacher to give children individual help

or offer assistance in providing special activities and meeting emergencies?

A full and stimulating day is just as important for a child with a handicap as it is for any other child. Are music and art, discussions of current events and other enrichment programs integrated into the routine?

Will your child have the special instructional materials that work best for him? Is appropriate exercise equipment available? Is physical education, adapted to your child's needs, available on the same regular basis as that offered to the other children?

Does the program include learning the skills of daily living? Is there an effort made to strengthen human "getting-along" abilities as well as practical how-to skills such as cooking, shopping, using public transportation? For the adolescent, needs increase in complexity and a well-rounded program for the older child should encompass these needs.

Is career education and vocational education part of the educational plan? Be sure that your child has ample opportunity to consider the range of career options available to all people—and is not hemmed in by stereotypes about what disabled people can or cannot do. Shop, home arts and other pre-vocational classes should be open to handicapped students and *can* be, by adapting teaching and equipment. These preparatory courses can open the doors later to vocational education and job training for your son or daughter.

Are recreational skills encouraged? Will your child have the opportunity to take part in extra curricular activities, school clubs, and social life? In other words, will the program help lead to a satisfying future?

Parent-teacher teamwork

You and the people responsible for the education of your child have the same goal: to make sure your child has an education suited to his or her individual needs. It takes real teamwork to bring that about. You can help make that teamwork happen. We've spoken of the importance of communication with your child's teacher. Here are some hints for strengthening the relationship.

Throughout your child's school years, continue your record-gathering, your observing, your information sharing. Keep your notebook current. Visit the school. Introduce yourself to your child's teachers, therapists, counselors, principal. Be sure to meet the school bus driver; he can be an important outside-of-the-school-building friend. Find ways to communicate information to the appropriate school people. Sometimes phone calls are appreciated; other times short notes delivered in the lunchbox work best. The more people know about your child's behavior patterns and the best ways to deal with them, the easier your child's adjustment to school will be.

Feel confident about meeting with your child's teacher to help develop an educational plan that meets his special needs and to keep track of how things are going. In so many ways, you know your child best. Share your knowledge. What progress have you seen? What difficulties? How does he learn best? How does he act at home? With other children? What things does he like (or dislike) most? Bring samples of the work he's done at home. More important, bring your questions, concerns and suggestions.

Remember to be constructive, to be assertive without being aggressive. Listen carefully. Ask for explanations when you do not understand. Remember that teachers have a great many problems to cope with too. Perhaps at first you and the teacher (and other school people) may not feel comfortable about working together. Learning to be comfortable and to communicate as equals will take time and effort. Remember, any good relationship takes lots of patience and work.

Always be polite and stay calm, no matter what is said. Tact, a sense of humor, and the art of gentle persuasion are important qualities to develop in all relationships with those people responsible for your child's learning.

Be sure that you know, in simple, clear terms, what your child's teacher expects him to learn—and what steps are planned to help him meet these learning goals. Is the learning plan based on the evaluation your child received? Have his strengths and weaknesses been fully considered? Does the plan take his pace and learning style into account? Find out how you can help at home. What ideas can you use to encourage progress? The richer the give-and-take you can establish, the more success you will see.

Don't give up!

There are times when you seem to be getting nowhere. Despite your efforts, the school system has not provided the program your child needs. What can you do?

First, learn about all the special education services available in your school system. You may be unaware of a program that *could* help your child. Borrow a copy of the policies and procedures guidebook used by the school district in which you live from your local school, library, or parent group. Get in touch with your State Director of Special Education and request information about state mandates and state laws for the education of children with handicapping conditions.

Next, learn what the chain of command is in your own school system. Place calls or send letters to the appropriate school officials describing the situation and what alternatives you suggest as solutions to the problem. Be sure that the superintendent of schools in your district is aware of the situation. If information is conveyed to you by telephone, be sure to ask for a letter of confirmation so that your record is complete.

The local Board of Education should be made aware of serious problems related to lacks in services for handicapped students. Letters to Board members and appearances before the Board can result in help for individual problems and can also lead to planning for new programs.

Be sure that the appropriate people in the office of the State Special Education Director really are aware of your child's situation and that they have all the necessary documentation. Your State Special Education Director may be conscious of the gap in services you are experiencing and may need you as an ally in working for increased funds for additional programs.

School systems now have step-by-step due process procedures to give parents the opportunity to appeal when their child has been placed in the wrong kind of class or denied the special educational help he needs. These procedures are there to protect you, and can only be effective when parents and schools make them work. Inquire at the office of the State Director of Special Education. Ask where hearings are held and for information on how to go about requesting one. Find out who may speak on your child's behalf at such a hearing. You may, for instance, want to ask a psychologist, social worker or classroom teacher to describe your child's problem. In other words, be sure to avail yourself of the opportunity you have been given by the system in its effort to be responsive to the special needs of children.

Join the efforts of parent groups and professional or citizen organizations that are working for better educational services for children with handicaps. These groups have been in the vanguard of the effort to improve education for handicapped children and youth.

Planning ahead

All of us hope for a life that holds meaning, self respect, love and fulfillment. People with disabilities are no exception. As your handicapped child grows, it's important for you to foster his or her strengths as an independent, self-reliant human being, just as you would for any other child. You have planned and worked so hard for opportunities to help him through the early years, it's sometimes hard to give up, to let him do the planning himself. He has the right to experience the risks and the challenges on the way to adulthood.

Disabilities vary in severity, and these words apply in differing degrees. But it's too easy to underestimate the capacity of a teenager or young adult to exercise his own judgment. Mistakes are inevitable. You are still there as a guide and mentor.

The following are some of the opportunities that are open to disabled young men and women as they (and you) plan ahead.

More and more colleges and universities have become accessible to students with handicapping conditions. Many young people with handicaps go on to college programs, pursuing their own special interests, extending their knowledge, sharpening their talents, and broadening their horizons alongside their non-handicapped peers.

Offices have been established on many college campuses to help students with handicaps locate resources that will ensure their full participation in college life: interpreters, readers, note-takers, tape recorders, tutors. Ramps and reserved parking places are an accepted part of the current scene. There are frequently adaptations in curriculum as well. Check the reference room of your library for catalogs and listings of college programs geared to the student with special learning needs. Write to HEATH/Closer Look Resource Center (Box 1492, Washington, D.C. 20013) for ideas and information about postsecondary programs.

Not everyone goes on to college. Other types of programs are essential, and it's important to know where to find them. Vocational education programs for young people with handicaps should be provided by public high schools. Check with your school principal or your local special education office to find out about existing programs. Explore potential vocations with your child in his early teenage years. As mentioned earlier, education plans should include vocational preparation; be certain the services provided are consistent with your child's aptitudes, interests, and needs. Get in touch with the State Director of Vocational

Education to make sure plans are under way to expand opportunities for public vocational education for students who are handicapped. Many community colleges are now offering vocational programs for disabled students and can serve people within a wide geographic area.

Call your local community college for courses and offerings that might be of particular interest to a student looking for classes close to home. Remember, too, that adult education programs in your community and the "Colleges for Living" often found on community college campuses across the country frequently offer classes in self-help skills geared to adult needs: managing a budget, balancing a checkbook, meal preparation, how to prepare for a job interview. Check the library, the adult education department of your local school system, or a local organization concerned with disabilities.

The Vocational Rehabilitation program, which operates throughout the country through a network of state and local agencies, provides a wide range of services, including occupational training, to help persons with handicapping conditions become employable and find jobs. Local offices exist in almost every major city. They are generally listed under "Vocational Rehabilitation" in telephone listings for city, county or state services. There are two basic qualifications for receiving services: an individual must have a physical or mental disability which constitutes "a substantial handicap to employment," and a "reasonable expectation" that employment preparation will be successful. (Employment can mean a job in the working world, sheltered employment or homebound work.) Certain services, such as diagnosis and evaluation, counseling and job placement, are free everywhere. Some states, however, require that individuals pay, depending on their income, for certain specified items such as medical care, transportation, books and equipment. Find out more about vocational rehabilitation services through the high school counselor or by calling the Vocational Rehabilitation office directly.

The U.S. Employment Service office in your area may have a counselor trained to be of assistance to handicapped job-seekers. Call your parent group for names of local employers who are hiring people with handicaps. Encourage your son or daughter to be creative, and also realistic, in job-hunting. Once a job has been secured, try to arrange on-the-job counseling service through Vocational Rehabilitation to help during the important first period of job adjustment. An important resource in learning about employment of disabled people is Mainstream, Inc., 1200 15th Street, N.W., Washington, D.C. 20005; telephone (202) 833-1162.

Information about sheltered workshop employment is available through vocational rehabilitation agencies. These workshops can give persons who are too severely handicapped to compete in the job world, or not yet ready to go out on their own, a chance to improve their skills

and work for pay under close supervision. Workshops often have contracts with business firms and industries to do certain jobs for fees, and should be seen as a dignified and purposeful part of the nation's labor force.

For some severely disabled persons, even a sheltered workshop is not a feasible goal. Day Activity Centers operated by public and private agencies can give them a chance to work at special tasks and develop as much independence as possible. Parent groups or Easter Seal Societies should be able to tell you if such programs exist in your community.

Opportunities for vocational training, jobs, sheltered employment and other kinds of work still lag far behind the need. Communities differ a great deal in their responsiveness to the right of people with disabilities to lead normal, useful lives. Services offered by vocational rehabilitation agencies vary widely in scope and in ability to give adequate help. If you or your handicapped son or daughter have not received services you feel you are entitled to from your local vocational rehabilitation office, you have the right to ask for a hearing about your grievance. Write to the State Director of Vocational Rehabilitation explaining the problem and requesting an appeal.

As you explore future options with your teenaged son or daughter, check out the housing opportunities in your community and state. More and more apartment buildings are being built with adaptations for people with physical disabilities. More and more severely disabled people are looking to the community rather than nursing homes for opportunities in independent or semi-independent living. Public and private agencies are opening group homes and apartments with live-in counselors for adults who need supervised living arrrangements. Explore all the options and be certain that your son or daughter is on the waiting list for every appropriate setting. Local chapters of organizations of and for disabled people are good sources of information about housing choices. Check, too, Vocational Rehabilitation, local United Way organizations and other community resources.

Note: In addition to local and state housing authorities, the federal government also provides assistance and information through the Office for Independent Living for the Disabled, Intergovernmental Affairs, Department of Housing and Urban Development, 451 7th Street S.W., Washington, D.C. 20410.

Centers for Independent Living are springing up throughout the country, helping adults with a variety of disabilities prepare for—and find—community living arrangements. A list of these centers may be obtained from: Department of Education Clearinghouse on the Handicapped, 400 Maryland Avenue S.W., Room 3106 Switzer Building, Washington, D.C. 20202.

It's vitally important to remember how much social and recreational activities add to meaningful living in adult years. As you think ahead, help your child learn leisure-time skills that will make the rest of his life more enjoyable. As he is growing up, include your child whenever possible in the recreational activities shared by the rest of your family. Encourage hobbies—gardening, swimming, bowling, basketball, exercises, reading, learning to play musical instruments, taking care of pets. You will think of others.

Check out the recreation programs and summer camps in your area. Are scouting programs a possibility? What about community centers or the Ys? You will, of course, need to use judgment in involving your child in a regular community recreational program. Is there a staff member available who is experienced with children with disabilities? Will efforts be made to adapt activities to match your child's needs and abilities? Will the other children be in the right age range? Can your child handle this new situation? You may need to be involved initially as an active adult participant in some group activities. You may even have to create opportunities where there are none, using that art of gentle persuasion you have cultivated.

If your child is seriously handicapped, you will need to search for specialized programs. Many city or county recreation or park departments provide special programs. Therapeutic horseback riding classes have become very popular. Call your parent group for suggestions. Check with the recreation department at nearby universities to see if a therapeutic activity clinic is operating. Helping your child know how to play, to find pleasure in leisure time activities, may be among the best gifts you can give.

During adolescence and beyond, every young person needs to move out of the family circle and find his or her own personal identity. Social activities become even more crucial during these years. The growth of adult self-help groups has been a big boost to young people seeking meaningful independent relationships. There are a great many excellent books on sexuality, written by and for disabled people; these can be encouraging and helpful. Check your library and Centers for Independent Living for good references. Adolescence is a difficult period for everyone: extra problems emerge for disabled teens. Reassurance is deeply needed: that their minds and bodies are acceptable; that they are loved and admired for their own fine qualities; that their determination and courage will bring them their share of life's rewards; that *each* of us is imperfect and needs guts and drive to make it as an adult. All of the investment you have made as a parent will help to build the launching pad for the adult years.

As your child is growing up, be sure that he or she gets to know men and women who have disabilities and are leading independent, productive lives. More and more people with handicaps of all kinds are living on their own, holding down jobs, entering every type of

professional field. These people are models for your son or daughter—not superstars, but everyday people—full-status citizens of the American community. Knowing confident adults with disabilities will help build optimism and a firm sense of self-worth.

One final caution as you look to the future for your child: one of the more difficult problems faced by parents of severely handicapped children is planning how their children's needs will be met when they're no longer around to monitor programs, provide support, and contribute financial stability. Answers are not easy; sometimes even knowing the questions to ask isn't easy. Parent groups often have written material that will help you to formulate your thoughts. They may also be able to help with names of competent lawyers who have some knowledge of handicapping conditions and the life care needs of people who are disabled, as well as empathy for the rights and needs of the rest of the family. Consult with a lawyer, make decisions, have the necessary legal instruments drawn up, and review those legal documents periodically.

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Where to turn for financial aid

Children with handicapping conditions do cost more to raise than non-handicapped children. There may be expenses for diagnosis, therapies, aids and appliances, extraordinary medical or dental treatments, diet supplements, special clothing, transportation, special schooling and child care needs. Insurance plans can help with medical costs and there are public and private benefits and services that should be explored.

One important financial support is adequate health insurance coverage. Be sure to investigate carefully just what your group or family insurance plan covers. Look for basic benefits, protection against major medical problems, whether or not psychiatric expenses are covered. Be very certain that your handicapped child is covered along with the rest of the family. Since at age 19 most children are dropped from family policies unless they're full-time students, find out early whether your dependent handicapped child can continue to be covered through his adult years.

Your child is entitled to a free, appropriate public education. If an appropriate public school program exists, the school system will not pay for a private placement. If you can establish through mutual agreement with the school or through a due process hearing that the intensity of services your child needs is not offered by the public school system and can only be provided in a private setting, the school system must purchase that education for your child. Call the local special education office and your state department of education for information about the procedures for obtaining tuition aid for special placement in private school.

Every state has a crippled children's agency which provides for diagnostic services without charge for children under 21 who may have handicapping conditions. The agency may also advise parents about treatment, help them find appropriate care, and assist in financial planning. It may assume part or all of the cost of care, depending on the child's condition and the family's resources. To find out when and where a clinic is held nearest your home, ask the state crippled children's agency, or your local health department. The handicapping conditions included in this program vary. Some states have broadened their programs to include children with many kinds of handicaps or long term illnesses.

The Federal Supplementary Security Income (SSI) Program provides monthly payments to disabled adults and to children whose families have little or no income or resources. The amount of these

benefits varies from state to state. Check with your district or branch Social Security office for answers to all questions about eligibility for this program and other related benefits. You will need your notebook in order to provide copies of medical records.

You may be eligible for certain income tax deductions for costs related to your child's care. Review the newest Internal Revenue Service publications dealing with deductions for medical and dental expenses, child care, and disabled dependent care. Your nearest IRS office can supply brochures that will be helpful.

The Junior Chambers of Commerce and other local fraternal organizations (such as Kiwanis, Lions, etc.) may have programs to help meet some of the special costs involved in raising a child with a handicap.

If you are an Army family, consult your local Army Community Service Organization to determine whether you are eligible for the health benefits and assistance available under the CHAMPUS program. If you are in the Air Force, contact your base CHAP officer. Navy families should contact their base Health Benefits Counselor.

Be sure to investigate fully the availability of scholarships or subsidies offered by private institutions or other programs in which you may want to enroll your child.

College and university financial aid offices can assist your son or daughter with information about scholarship, grant and loan funds. The federal government has a variety of programs which you may learn about by writing to: BEOG, P.O. Box 84, Washington, D.C. 20044. Be sure to check with guidance counselors, school and public libraries for handbooks on private financial aid programs.

Vocational Rehabilitation can provide financial assistance with special aids and transportation needed to participate in an educational program leading to employment. Eligibility and possible help should be explored.

For additional help in finding sources of financial asistance, we suggest you get in touch with a family service agency in your community. A social worker who knows your community well may be able to think of other ways to lessen your financial load.

Bridging the information gap

The parents of a child with a handicap often need the skill of a detective to dig for the special services and resources they need. It is never *one* thing they are searching for, but many. Often, it is even hard to know where to start looking. Fortunately, there are people who make it their business to know about diagnostic centers, counseling, camps, transportation services, specially trained baby-sitters, tutors, doctors and dentists who treat handicapped patients, and other needs that are likely to be on a parent's list.

Information and referral services which can lead you to a variety of community and social service resources are provided by United Way organizations, public libraries, and some public health or social service agencies. These information and referral centers can sometimes help families with handicapped members by providing supportive services such as transportation to and from clinic and therapy appointments.

Easter Seal Societies usually have a storehouse of knowledge about diagnostic services, education programs, therapy and recreation for *all* handicapping conditions. (Many have their own educational, vocational and treatment programs for a variety of conditions too, including programs for special learning disabilities, speech and hearing impairments, mental retardation, etc.)

Use the yellow pages of your phone directory to look up public, voluntary, or private agencies that may be able to supply the kind of service you are seeking. You will find them under the heading "Social Service Organizations." The title of the organization may suggest the service it performs; but even if you don't locate what you're looking for on the first try, you will probably find that the person you talk to can refer you to a more appropriate agency.

Other parents who have experienced problems similar to yours may be the best source of information of all. Be sure to check with your local parent groups for answers to questions about where, when, and how to get what you need.

Why join a parent group

We've talked a great deal about parent groups in these pages. Their importance really can't be over-emphasized. The progress that has come about since the 1950s has been largely the result of their pioneering efforts, and they continue to break new ground for people with handicapping conditions. From the point of view of the individual parent, their greatest value is probably the unique kind of understanding and support they can give. Parents strengthen one another, and, by joining hands, are often able to accomplish miraculous changes in their own communities.

Many of the services you are loooking for, such as preschools, camps, education and job training programs, were originally started by parent groups. Also, as we've pointed out, members of these groups are often experts on hard-to-find services. They have know-how that comes with experience, and can act as guides through the bureaucratic maze. They issue newsletters, compile directories, circulate lists of reading material, hold workshops, sponsor support groups, and train volunteers and advocates. Of course, groups vary in effectiveness, but it is clearly worth your while to find out what yours has to offer.

These groups can be particularly helpful in meeting the new needs that arise as your child grows to adulthood. In many communities, they sponsor social and recreation programs which are filling the void that too often arises for teenagers and young adults who aren't able to keep up with their non-handicapped peers.

Parent groups have also made headway in creating more normal ways of living for those who have, in the past, had no alternative to institutional life. They have helped to develop group homes and other living arrangements that offer a life style that includes friends, jobs and recreation.

Parent groups representing different disabilities have joined together in many areas of the country to create strong and effective coalitions. Local and state governments, local and state Boards of Education, and local and state legislators have listened to their combined voices and heard their reasoned arguments for changes that will affect the many, rather than the few. More often than not, public officials have responded in helpful ways.

An exciting new kind of group has appeared on the scene in recent years—self-help or self-advocacy groups. Adults with disabilities are meeting together over matters of common concern. They understand one another's problems, share resource information, and support

one another in their efforts to become independent, contributing members of our society.

There are now hundreds of organizations formed by parents, or by people who are disabled. If you have difficulty locating an appropriate organization, write to Closer Look. We can put you in touch.

About attitudes

We have lived through a great change in our most recent history; there has been a revolution in attitudes toward people who are handicapped. A profound surge of awareness of the dignity and human rights of people with disabilities has stirred action on many levels. The blatant discrimination that existed for centuries has been challenged. New opportunities have opened where doors were shut . . . for infants born with severe handicaps, for children who need individualized teaching, for disabled men and women seeking freedom to live and work in the community. A better world is out there, a world which is coming to understand that people with handicaps can be part of every aspect of life.

The best part of the new attitude is that it really includes all of us. It says not only that we *all* belong to the human family, but also that nobody is perfect . . . that we all have our own personalities, our own unique abilities, our own strengths and weaknesses, ways in which we are attractive and other ways in which we are less than appealing. We can appreciate any child's own individual beauty—whatever it is, no matter how seriously handicapped he may be.

That doesn't mean that life has become easy sailing for parents of handicapped kids. The world *is* making progress, but it's uneven. We deal with some professionals who still convey the message that our children are not really worth such a tremendous investment of time and energy. We see people stare at our children with pity or else turn away quickly with averted eyes. Even the comfort we seek from our own families is often not there and we realize that we must be their comforters, their patient teachers.

It's hard to keep one's balance, to decide to try again when things fall through. Life can be grim, and part of the job of living with the problems of handicaps is not to let it be. When it does get too tough, it's good to realize that you can seek advice and counseling from professionals who can help you and your child strengthen your ability to handle your world.

It's good, too, to build into your life strong support systems that can keep you going, that can help you regain perspective when everything seems too much to handle. All over the country, "respite (relief) care" services are springing up offering temporary care of the person with a disability so that the rest of the family is allowed time to relax, freedom to socialize, relief from the daily routine. Using experienced caregivers provides a benefit to the child with a disability as well. It affords the child a chance to grow, an opportunity to learn trust in someone outside of his immediate family members. Find the respite service in your own

community. If it doesn't yet exist, suggest to your parent group that one be started. It can help.

Parents of children with handicaps carry still another responsibility—one that can have far-reaching effects on the community in which you raise your children. You can be a quiet educator, an attitude-shaper in your neighborhood, in your own city or town. When you are ready, take your child with you on trips into the community. Smile. Hold your head high. Answer the curious questions of the young so that they will not continue the fears and prejudices of former generations. Help your handicapped child's brothers and sisters to be teachers, too—by fortifying them with information, by allowing them to take part in family decisions, by letting them talk out their feelings.

Developing a relaxed attitude, looking for the humor in frustrating situations, isn't easy. Parents can fall into a trap of pushing endlessly for more and more "training," "motor coordination," "speech therapy," whatever, and forget to enjoy the child himself.

A child who lives with fun, with parents who can keep their perspective, will be building the foundation of his own satisfying life. He will be able to see what he *can* do, what he *can* enjoy, what life *does* offer that is worth working for even though the going is rough. And that's what it's all about.

About the authors...

Barbara Scheiber is Executive Director of Parents' Campaign for Handicapped Children and Youth and author of numerous articles and pamphlets for parents. She is the mother of a young man with learning disabilities.

Cory Moore is the mother of three children—her middle child is a multi-handicapped adolescent. She is currently Parent Information and Education Coordinator for The Montgomery County (Maryland) Association for Retarded Citizens. She is co-author of *A Reader's Guide for Parents of Children with Mental, Physical, or Emotional Disabilities,* published by the Department of Health and Human Services.

Special appreciation to Marie Ormsby, Project Manager of Closer Look, for her work in editing and producing this pamphlet.